

**Improving diabetes care for people with intellectual disabilities:  
A qualitative study exploring the perceptions and experiences of professionals  
in diabetes and intellectual disability services**

**Abbreviated Title**

Improving diabetes care for people with intellectual disabilities

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## **Abstract**

**Background:** Globally diabetes is increasing with concerns about the impact on outcomes, including premature death and the costs associated with managing the condition. Research indicates that adults with intellectual disabilities (ID) are 2-3 times more likely to develop diabetes; however there has been limited focus on diabetes service utilisation in this population. The aim of this study was to explore the perceptions and experiences of diabetes and ID practitioners.

**Method:** A series of 1:1 semi-structured interviews were undertaken in one Scottish health service area. In total n=29 qualitative interviews were conducted; ten with diabetes practitioners from primary and secondary care and fourteen from ID services and five from community care services regarding diabetes service provision for this population. Thematic content analysis was undertaken to identify the themes and sub-themes.

**Findings:** Three main themes were identified: (i) Enabling access to services to meet diabetes related care needs of people with ID; (ii) Communication and service improvements between staff, patients and across services; and (iii) Providing person-centred diabetes care and developing adapted resources to increase patient self-care.

**Conclusions:** The findings of this study have important international implications in how diabetes practitioners plan and deliver services for people with ID and other vulnerable groups with limited cognitive ability, limited communication skills and difficulties in self-management. The findings highlight that access to diabetes education and adapted resources is needed and if 'reasonable adjustments' are made to service provision and practice, people with ID can benefit from improved healthcare. Developing joint clinics to share knowledge and resources between diabetes and ID practitioners may improve service delivery and continuity of care, and thereby diminish the costs of not providing quality care.

**Keywords:** Intellectual disability, learning disability, diabetes, practitioner experiences, service provision, qualitative research

## INTRODUCTION

It is estimated that globally 347 million people have diabetes (Danaei et al., 2011). The World Health Organisation has projected diabetes will be the seventh leading cause of death by 2030 (WHO, 2011). In the United Kingdom, the Quality Outcomes Framework Data (QOF) has standardised the delivery of primary care medical services to enable the treatment of common conditions, such as asthma and diabetes, the management of health concerns including smoking and obesity and the promotion of preventative care, for example, routine monitoring of blood pressure. The QOF national quality indicators provide primary care with the standards of care to be provided to patients, including conditions such as diabetes, thereby ensuring it is a core element of routine clinical practice (NICE, 2011a; Department of Health, 2008a; 2001). Data analysed as part of the QOF suggests the prevalence of diabetes in the non-disabled population in 2013 is about 6%, equating to some 3.2 million people (Diabetes UK, 2014). While there is a well-developed evidence-base regarding diabetes care for the non-disabled population, the evidence regarding the prevalence and needs of people with intellectual disabilities (ID) is growing and evolving. Little known about the management of this population's diabetes and the issues and challenges this presents to practitioners (Taggart et al., 2013; 2015b). This is the first study to explore the service utilisation and healthcare received by adults with ID from the perspective of both diabetes and ID practitioners.

Care services for people with ID have undergone significant changes over the past decades, with moves away from institutional to community-based models of care (Shakespeare 2006). These changes have been informed by a move away from a medical model to social model of disability, with a focus on changing negative and discriminatory attitudes and the removal of barriers to equality of access to services, care and support, rather than biologically based that seeks to 'cure' people with disabilities, further contributing to their social exclusion (Barnes & Mercer 2010). Despite these developments, many people with ID experience high rates of medical consultations, hospitalisation and premature deaths compared with the non-disabled population resulting in reduced quality of life, avoidable ill-health and additional cost and burden on families and care services (Emerson et al., 2012a; 2012b; Glover & Ayub, 2010; Tyrer et al., 2007; Lloyd et al., 2013, Emerson & Hatton, 2014, Taggart &

Cousins, 2014). Evidence suggests that while life expectancy of people with ID is advancing (Bittles et al., 2002; Scottish Government, 2013) actively addressing the health inequalities is required as highlighted by enquiries, investigations and policy reports (Department of Health, 2008b; Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 2009; Department of Health, 2009a; 2009b; 2010; Mencap, 2012; Heslop et al., 2013). Practitioners in universal or mainstream primary and secondary healthcare services have limited knowledge and experience of the needs of people with ID: which contributes to their lack of confidence in providing care and support and leads to further disadvantage and poor health outcomes (Gibbs et al., 2008; Bradbury-Jones et al., 2013).

People with ID have poorer health and a higher prevalence of health conditions than the non-disabled population (Baxter et al., 2006; Jansen et al., 2004; Public Health Services, 2002; Lin et al., 2003; Haveman et al., 2010; Glover et al., 2012; Imran et al., 2013). There is an increasing focus on investigating the complex physical and mental health comorbidities experienced by adults with intellectual disabilities, with studies highlighting prevalence rates of diabetes in people with ID ranging from 0.4% (Goldacre et al., 2004) to 18.5% (Reichard & Stolzle, 2011). A recent population-based cross-sectional analysis findings added further weight that multimorbidities, including diabetes, are more common in adults with intellectual disabilities and occur at an earlier age (Cooper et al., 2015). Reasons for the prevalence rates are based upon issues, including, the definition of ID, whether people with ID are screened for diabetes, and whether they are known to primary healthcare services and flagged as having both ID and diabetes on their clinical notes (Taggart et al., 2014; 2015a).

Studies suggest that both Type 1 and Type 2 diabetes are more prevalent in people with ID than the non-disabled population (Taggart et al., 2013; 2014; 2015b; Reichard & Stolzle, 2011b; Straetmans et al., 2007; Haverkamp et al., 2004; Lunskey et al., 2011; Goldacre et al., 2004). A systematic review by McVilley et al. (2014) concluded that the prevalence of diabetes in people with intellectual and developmental disorders remains unknown; although the evidence states that this population is at greater risk of developing diabetes. A further systematic review undertaken by MacRae et al. (2015) suggested a prevalence rate of diabetes in the ID population of about 10%, and

highlighted the need for greater access to support and diabetes self-management education programmes specific to the needs of people with ID.

Two studies have been undertaken which have evaluated the quality of diabetes care received by people with ID in Canada (Shireman, 2010) and in Northern Ireland (Taggart et al, 2013), with findings highlighting that national standards for diabetes management are only partially met for this population. Cardol et al. (2012a) explored the experiences of ID residential staff in the Netherlands and reported that diabetes care was directed towards administering medication and dietary control with little focus on self-management behaviours: this was linked to limited diabetes training per se. Trip et al. (2015) undertook a qualitative study involving n=17 support workers in New Zealand regarding their role in supporting self-management of diabetes. The study identified the need for further education for people with intellectual disabilities and both permanent and casual staff to promote self-management and build confidence, with a view to reducing health inequalities. Whitehead et al. (2016) undertook a qualitative study in New Zealand involving 14 people with intellectual disabilities with type 1 and 2 diabetes and n=17 support workers focusing on negotiating autonomy in diabetes self-management. The authors identified processes of negotiated autonomy into the management of diabetes, within the context of risk and patient safety.

While there is a small and growing body of research about the needs of people with intellectual disabilities and the role played by their support workers in the effective management of their diabetes and in enabling self-management, no studies to date have explored the perceptions and experiences of diabetes practitioners in primary, secondary healthcare and specialists in ID services. Therefore, with the increasing population of people with intellectual disabilities living into older age, many with complex multimorbidities, there is a need to better understand the needs of the practitioners across health and care services who meet the care and support needs of this population. The present study therefore seeks to start to address this issue.

## **Aims**

In light of the limited evidence, the aim of this study was to explore the perceptions and experiences of health and social care practitioners caring for people with intellectual disabilities who have diabetes, and identify their education needs and

service development opportunities. There were two study questions: 1) what are the perceptions and experiences of practitioners regarding the care and treatment to people with ID and diabetes and 2) what are the barriers and possible solutions to improving diabetes care and service delivery for people with ID?

## **METHOD**

### **Design**

This was a qualitative study conducted in Scotland that employed one-to-one semi-structured interviews to collate the data. Using this data collection technique allowed the research team to explore in-depth the diabetes and ID practitioner's perceptions of their experiences of working with and caring for adults with ID and diabetes (Parahoo, 2014).

### **Recruitment**

Table 1 shows the study participants. In total ten diabetes practitioners from primary and secondary diabetes services, and fourteen specialists from ID teams and support workers from a social care community residential service in one health service area in Scotland. A sample of n=29 health and social care practitioners consented to participate in one-to-one interviews in 2014. Participants were selected purposefully from across health and social care services to reflect variation in practice roles and experiences. The diabetes practitioners were required to have direct experience of caring for people with intellectual disabilities with diabetes in the past year. The support workers were recruited from a single social care community residential service as it was the largest care provider in the area, with experience of supporting people with intellectual disabilities with diabetes in the past year. All potential participants were recruited via their line managers and provided their written consent before being contacted by the research team. When no new data was identified within the interviews, the research team agreed saturation had been reached within these interviews and no further data sought (Parahoo, 2014).

TABLE 1 ABOUT HERE

## **Ethics**

As this study was part of a larger UK study (removed for review), the (removed for review) Office for Research Ethics Committee granted ethical approval. All participants provided their informed written consent prior to interview. All research ethics and governance procedures were adhered to throughout.

## **Data collection**

A semi-structured interview schedule was developed and piloted from findings within the extant literature, and was further informed by the research team's clinical experience of the care issues, thereby making the design theoretical and thematic rather than inductive. Interviews lasted between 30-45 minutes. There were three key sections to this interview format: i) several questions focussed on the participant's experiences of working with adults with ID and diabetes, such as diabetes literacy used, screening, treatment regimes, self-management strategies, diabetes education and support needed; ii) challenges in working with this population and iii) solutions to overcoming such challenges. All participant interviews were recorded using a Dictaphone and transcribed verbatim and identifiable information removed to ensure anonymity.

## **Data analysis**

The data analysis followed the 6-phase structure of thematic analysis as suggested by Braun & Clark (2006). The data were uploaded in their entirety to NVivo 10 for initial coding. Content analysis was undertaken by focussing on the research questions and to identify contrasting responses between participants, thereby identifying new and novel findings (Braun & Clark, 2006). The codes were collated into themes and subthemes, named and reviewed by the research team to identify those most commonly recurring. The 4 aspects of qualitative research of trustworthiness, credibility, transferability, dependability and confirmability, as identified by Guba (1981), were upheld throughout through sample recruitment, respondent validation, peer examination, step wise replication to enhance the rigour of analysis process (Krefting, 1991). To ensure the robustness and rigour of the analysis process, participants were invited to verify accuracy of their transcript and make any further additions. An integral part of the data analysis process involved taking field notes

during the interviews which assisted the research team to identify important and relevant themes and formed the basis of further discussions and agreement. Subsequently, to ensure an iterative process, all transcripts were reviewed and coded individually by the research team members and then collectively as a group and the themes and subthemes discussed and agreed.

## Findings

Three main themes were identified: (i) Enabling access to services to meet diabetes related care needs of people with ID; (ii) Communication and service improvements between staff, patients and across services; and (iii) Providing person-centred diabetes care and developing adapted resources to increase patient self-care. The three themes and their sub-themes are set out in Table 2.

TABLE 2 ABOUT HERE

### Theme 1: Enabling access to services to meet diabetes care needs

There were three sub-themes identified within this theme: the impact of cognitive limitations on diabetes service providers, care and support issues experienced by health and social care practitioners, and time and access to information and resources in the clinic setting.

#### *The impact of cognitive limitations on diabetes care providers*

All participants highlighted how the level of ID, comprehension and communication skills may impact on their understanding and acceptance of a diagnosis of diabetes, the recognition of the long-term implications of diabetes and the treatment regime, including diet, exercise, medication and self-management.

*'If someone doesn't have a good memory for taking medications, how do they get medications given? If someone doesn't understand what you're trying to do, you know, it's actually very difficult to get engagement and their cooperation. So all these things just make it very difficult to manage the diabetes.'* (Diabetes Physician 3)

In addition, many of the participants' also highlighted issues that people with ID may experience in participating in diabetes self-management education programmes now



routinely offered to the non-disabled population. A range of factors were identified, including the 'content' of the education programme as being too complex, 'language' and 'terminology' used by participants within the group, the 'duration of the group' as being too long and the 'impact on other group members' due to the specific needs of people with intellectual disabilities and their learning pace.

*'If someone doesn't learn easily, how do you get behaviour change? If someone doesn't understand why you're trying to do things, it's actually very difficult to get engaged with their cooperation.'* (Diabetes physician 1)

*'The sessions are too long. It's a lot of information and they might not be able to concentrate for that length of time.'* (Diabetes Specialist Nurse (DSN) 1)

#### *Care and support issues experienced by health and social care practitioners*

Many of the diabetes practitioners described how people with moderate to severe ID require family or paid carers to enable the person with ID to safely manage their diabetes, make healthier food choices and support them in the change and decision-making process. In contrast, practitioners in ID residential services and ID dieticians reported that people with milder ID often lead more independent lifestyles, giving more opportunities to make potentially unhealthy food choices that have impacted upon poorer diabetes control and self-management.

*'A lot of what goes on with carers is the fear of not feeding them enough and therefore being berated because they've been too restrictive.'* (ID dietician, 2)

*'We'll be out shopping and she'll say 'oh let's get a trifle or these cakes' and you worry how often she's buying things like this when she's not supported.'* (ID residential staff, 1)

#### *Time and access to information and resources in the clinic setting*

Diabetes practitioners recognised that some people with ID required additional time within the clinic, more focussed and targeted diabetes education and support when attending out-patient appointments and that this can present difficulties during 'busy clinics', limiting the possibility of providing person-centred care.

*'You just get rushed through these appointments. You have ten minutes, no doctors and nurses have got time to sit and explain diabetes in a way that people with ID can understand...they're always so busy.'* (ID residential worker, 1)

Some respondents also reported 'a lack of accessible information' for people with ID and their carers about diabetes, management and potential complications. Some diabetes and ID practitioners described being unaware if accessible information about diabetes existed and where to obtain them. However, in contrast, some respondents such as the diabetes specialist nurses and ID nurses were of the view that there was easily accessible information available and that it is a case of knowing where to look.

*'The GP's can access easy read diabetes information on the NHS intranet.'* (DSN, 2)

The need to adapt information about diabetes and make it accessible for the individual patient by specialists in ID health services, included using Talking Mats, easy read materials and providing pictorial and symbolised information were given as examples of 'making reasonable adjustments'. While reasonable adjustments were required for some patients, it was recognised by ID practitioners that there were additional time and resource implications that need to be considered.

*'People with ID and diabetes require specialist input, tailored education programmes and treatment packages so that they can be fully part of their treatment plan, fully understand the condition and the lifestyle choices they have to make to maintain good physical health.'* (ID psychologist, 2)

## **Theme 2: Communication and Service Improvements**

Four sub-themes were identified within this theme: the role of families in providing support, effective multidisciplinary working, education provision and service provision.

### *The role of families and paid carers in providing support*

Both groups of participants stated that the positive working relationships between ID practitioners and people with ID are crucial in enabling effective diabetes management due to their wider knowledge and expertise of the needs of the population. The development of social care support workers was seen as important as they are central to on-going compliance with treatment plans and provide support outside of diabetes education programmes, yet often had limited knowledge about diabetes.

*'The person with ID went along to the diabetic clinic with her support worker she had known for years. She learned a lot and it was a really positive experience.'* (ID psychologist, 2)

To enable access to mainstream diabetes services and out-patient appointments, some people with ID require additional support from family members or their support workers. This provided an opportunity for 'information sharing and clarification about diabetes management', 'with opportunities for closer collaborative working between diabetic and specialist ID services', thereby promoting more effective practice and coordination of care.

#### *Effective multidisciplinary working*

ID practitioners highlighted how they worked with specialist diabetes nurses to develop person-centred care and support for people with ID. By working collaboratively they identified, for example, 'the most appropriate insulin or medication delivery method', 'the indication for further clinical assessment' and the circumstances 'when additional support from ID liaison nurses were required'. Support workers described positive experiences when seeking guidance from diabetes services.

*'I work with a diabetic nurse sometimes, and we have good communication and we work out what's best for the person with ID in terms of support.'* (ID nurse, 2)

*'It's worked well when we've had multidisciplinary team meetings so that everyone's on board with the current medication regime and what to do in an emergency etc.'* (DSN, 2)

#### *Education provision*

Participants from all disciplines stated that improving the provision of education for family and paid carers about diabetes was necessary. All the support workers reported not receiving formal training about Type 1 or 2 diabetes. The participants from ID services also highlighted the on-going training needs of staff where 'high turnover of the workforce can be a significant issue' and took up resources and staff time. Both the diabetes and ID practitioners identified the need for dual training in both diabetes and ID, and that their colleagues would benefit from further training in their area of expertise.

*'Often it's the family or paid carer who's the gatekeeper to food purchase and intake so they need to be educated as much as the individual with ID.'* (ID dietician, 2)

*'I think probably a little bit of ID education would be good for us diabetes staff for sure.'* (Diabetes podiatrist)

#### *Service provision*

Inconsistencies in the care of people with ID by family and paid carers were viewed by diabetes practitioners as problematic in enabling effective diabetes management. This resulted in 'layers' of understanding and inaccurate communication with patients with ID and diabetes, thereby leading to confusion and poor management. This confirmed the need for improved communication and the development of networks between primary healthcare, specialist ID services, diabetes services and social care services who support people with ID and diabetes in the community, thereby promoting person-centred care.

*'Because people's health is so much more dependent on a system of support, not just their own autonomy, there are many more places it can fall down. You've not just got one person's attitudes, you have ten people's health attitudes.'* (ID psychologist, 2)

*'We don't have a direct pathway or network and so that might be a bit haphazard between dietetics, nursing and whoever else is involved in what we all do.'* (ID nurse, 2)

*'It's not always clear where someone with ID and diabetes' main care is being provided from and who by.'* (DSN, 2)

### **Theme 3: Person-centred care**

There were five sub-themes in this section: making reasonable adjustments to diabetes management and support, managing care within mainstream diabetes services, continuity of care, diabetes management and promoting self-management.

#### *Making reasonable adjustments to diabetes management and support*

Both diabetes and ID practitioners agreed the importance of person-centred diabetes management and support and referred to terms such as 'individualised', 'tailor-made' and 'specific' in relation to the most effective care for this heterogeneous population. The need to make reasonable adjustments to improve the persons' self-management strategies, for example diet, physical activity and smoking, were required to suit individual cognitive and communication abilities, lifestyle and personal circumstances.

*'Let's think about it from a person-centred approach. You don't want to say "this is how we offer it, you fit in or you don't", it should be "this is what we offer, how can we make sure you can gain from that rather than go away without having learned?"'* (ID psychologist, 3)

#### *Managing care within mainstream diabetes services*

Many of the diabetes practitioners agreed that the preferred model to provide diabetes care for this population is to receive their care within mainstream diabetes services with additional support from ID practitioners. One participant was of the view that 'a separate diabetes service would be stigmatising and inappropriate'. In contrast, the ID nurses suggested developing joint diabetes clinic for people with ID and more complex needs could be useful, thereby providing the opportunity to establish 'a shared care pathway' and a tiered approach to diabetes management across care services.

*'Why not have a joint venture between ID services and diabetes services? The more people that input, the better really.'* (ID nurse, 3)

*'There could be general diabetes information and then you step it up to more specialised information for the people with ID to meet their needs.'* (ID psychologist, 4)

*'The majority of people with diabetes are looked after in primary care now and only ones that come to a hospital environment are those that have got more complex management needs, often requiring multiple treatments or who are getting complications. That includes people with ID.'* (Diabetes Physician 2)

### *Continuity of care*

It was reported by participants that many people with ID and diabetes will require more frequent review by diabetes services and 'require longer appointment times' to ensure their needs can be assessed and management plans discussed and understood. Trying to ensure the patient has the 'same contact' with the same diabetes practitioners at each consultation was reported as important, yet challenging. The 'need for a designated diabetes nurse with an interest in ID', with whom other diabetes practitioners could consult and offer advice about management issues, was seen as one way to promote continuity of care. The role of ID support workers was viewed as key to effective continuity, with the need for clear documentation and protocols regarding their role in supporting people with ID and diabetes in their own home.

*'Have more acceptable contact points and times so that you're not stuck to a general outpatient template. So that you see them more regularly, and for a longer period of time within a structured clinical setting.'* (DSN, 1)

*'A constant face and engagement with an individual is important. So for individuals to come along to a particular diabetes clinic, and be seen by the same clinician.'* (DSN 2)

### *Diabetes management*

Exercising clinical judgement by setting alternative diabetes management targets for people with ID was seen as necessary to enable safe management by participants in diabetes services, such as 'a simplified insulin management plan', due to the risk of hypoglycaemia. Maintaining higher blood glucose levels than people with diabetes in the non-disabled population was justified by practitioners in diabetes services as necessary against the potential of developing further health problems in the long-term.

*'You can't realistically expect a community nurse to inject someone six times a day, you have to compromise on a once or twice daily management that can be managed within the constraints of the service.'* (Diabetes physician, 3)

*'You might aim for a less tight target because you're worried about hypoglycaemia, but that then makes the person, over many years, more likely to get complications of diabetes. You're almost caught between a rock and a hard place. We've been doing things that we think are helpful for diabetes, that actually might be not very good in terms of the overall care that that person gets.'* (Diabetes physician, 2)

### *Promoting self-management*

Empowering the person with ID to self-manage their diabetes was a common theme reported by participants from both diabetes and ID services. There was agreement across participants that current diabetes self-management education programmes available to the non-disabled population need to be 'adapted' and 'additional support with appropriate accessible information' provided to meet this population's needs and make such programmes accessible for people with ID. ID specialists highlighted that due to cognitive issues, 'an assessment of capacity to make decisions' about their care options and consequences may also be required, with further opportunities for joint working between services.

*'We need to increase people's autonomy, increase their informed choice, promote the idea that their health is in their own hands the way ours is. Historically people with ID have been reduced to being a passive participant and so it's about empowering them to be an active participant in their wellbeing.'* (ID psychologist, 2)

*'There's a course called DAFNE and which is a really intensive one-week course that people do to learn how to use insulin appropriately. No, there's no way in a million years that somebody with a learning disability could do that course; it's just not possible at all.'* (Diabetes Physician 1)

## **Discussion**

This is the first study to specifically explore the experiences of diabetes and ID practitioners in the management of diabetes in intellectually disabled population. The findings of this study have important implications internationally on how diabetes practitioners plan and deliver their services not only to people with ID but to other vulnerable groups with limited cognitive ability, poor communication skills and difficulties in self-management of this long-term health condition such as the elderly and people with on-going mental illness.

What emerges from the findings are people with ID and diabetes who are dependent on family carers, ID and diabetes practitioners, none of whom are fully equipped with sufficient knowledge, resources, accessible information, time and coordinated communication that enables person-centred care that adequately meets their needs and addresses the challenges they present to services (Taggart et al., 2014, 2015b). The findings from this study supports the need to focus specifically on people with ID and diabetes, necessary given the growing evidence of the increasing longevity and multimorbidities of the population and increased prevalence of the condition across the lifespan (McCarron et al., 2013; McVilly et al., 2014; Cooper et al., 2015; Macrae et al., 2015).

The findings from the current study builds on those from an earlier study that explored ID practitioners' views on diabetes care for adults with ID in the Netherlands (Cardol et al., 2012a), with the authors reporting a lack of appropriate diabetes educational material, competing work role demands and inadequate resources as barriers to diabetes care and positive self-management. Additionally, the study undertaken by Trip et al. (2015) in New Zealand supports the finding in the current study of the need for initial and ongoing education of support workers and improved collaboration and communication across services. The current study builds upon these findings by evidencing the need for diabetes management and care to be provided within mainstream diabetes services, improved diabetes and ID education, the need for improved coordination of care and information sharing within and across care teams, better collaboration between care practitioners and family members, and developing person-centred approaches to enabling self-management of their diabetes by people with ID.

The findings of this study have raised issues regarding the role and the need for service developments for both mainstream diabetes and ID services who provide care and support for people with ID and diabetes. Despite significant developments resulting from the implementation of the social model of disability, there continues to be barriers experienced by people with ID when accessing universal healthcare services available to the non-disabled population, of health needs being unmet and avoidable and preventable mortality (Alborz et al., 2005; Heslop et al., 2013; Emerson & Hatton, 2014; Taggart & Cousins, 2014). To promote and enable equality of access to universal health services, models of additional support, such as ID Liaison Nurses, have been recommended and may offer part of the solution in relation to diabetes management, education and care coordination (Brown et al., 2012; Iacono et al., 2014). Based within mainstream health services the liaison nurses work with people with ID, their families and healthcare practitioners to provide additional support and expertise to help ensure that people with ID have equality of access and health outcomes (Backer et al., 2009; Brown et al., 2010). Access to additional support is necessary as the findings from the current study highlights that practitioners in diabetes services have limited knowledge of the specific the support needs of people with ID; or of the role and structure of specialist ID health services; or the background of social care support worker who may accompany people with ID to out-patient appointments. Addressing these issues is necessary if care is to be both person-centred and safe (Brown et al., 2016). In contrast, practitioners in ID healthcare services and social care services lacked up-to-date knowledge regarding diabetes management (Cardol et al. 2012a; Taggart et al., 2013; 2014; 2015b; Trip et al., 2015). There is therefore an opportunity to develop shared learning that addresses these gaps in knowledge and competencies as a means to improve patient outcomes and diabetes management, promote coordinated care and improve communication and information sharing (Barr & Gates 2008).

A finding from this study is the possibility of developing and establishing shared diabetes clinics that involve practitioners from both diabetes and ID services, thereby drawing on the expertise of both. Joint clinics have been established in other areas of ID practice and are not new; examples already exist, such as for people with Down Syndrome, epilepsy and transition clinics to facilitate the transfer from child to adult services (Larner 2007; McGrowther et al., 2007; Camfield & Camfield 2011). Such a



new development could be helpful in meeting the needs of people with ID who have physical and mental health multi-morbidities, in addition to their diabetes, where care delivery is more complex and challenging, necessitating the need for new ways of working and multi-professional collaboration (Kwok & Cheung 2007; Dept of Health 2008b; Heslop et al., 2013; Cooper et al., 2015). Diabetes is increasingly managed within primary care, with practitioners such as GPs and practice nurses effectively managing the condition with the non-disabled diabetic (Khunti et al., 2012; Shaw et al., 2014). There could be scope for joint diabetes clinics to be based within primary care, involving GPs, practice nurses, diabetes practitioners and specialists from ID services as a way to improve communication, information and skills sharing throughout the care journey and across and between agencies with the potential to contribute to safe, person-centred care (Gucciardi et al., 2016). However, there is a need for empirical evidence regarding the outcomes and benefits from joint clinics and to ensure that new models are truly collaborative and do not lead to further exclusion (Jukes & Aldridge 2006; World Health Organisation 2010).

Ensuring that practitioners from diabetes, ID and social care services, receive diabetes education as part of their professional development is an area that requires attention. The need for education for social care support workers has been reported by Cardol et al. (2012a) and Trip et al. (2015) and is supported by findings from the current study. An important finding from this study is the need for education regarding the needs of people with ID for practitioners in diabetic services. Training for diabetes practitioners regarding the implications of cognitive impairments, the role of specialist ID services, capacity and consent, tailoring communication and utilising adapted literature and resources to educate people with ID about their diabetes. Practitioners in specialist ID services could benefit from diabetes updates to help communicate information in a way that is accessible to people with ID. Similarly, education is required by people with ID and their families regarding diabetes and issues such as self-management, important given the increasing prevalence of diabetes in the ID population (Cardol et al., 2012b; Dysch et al., 2012; McVilly et al., 2014; MacRae et al., 2015).

The cognitive limitations experienced by people with ID were viewed by some practitioners from diabetic services as a challenge to safe diabetes management. In the current study, diabetes practitioners highlighted prescribing modified insulin regimens to take the onus off patients with ID and type 1 diabetes, due to the belief

that diabetes information might be too complex for some people with ID, lacking an understanding of risks and consequences. These findings are in keeping with previous research by Bazzano (2009), suggesting people with ID are excluded from decisions about their health care and opportunities for self-management due to concerns about their cognitive limitations and autonomous decision making abilities (Cardol et al., 2012a; Dysch et al., 2012; Trip et al., 2015; Whitehead et al., 2016). Alternatively, the exercising of clinical judgement by experts in diabetes management can be justified in preventing the risk of hypoglycaemia.

Learning about diabetes and how to self-manage are the mainstays of diabetes intervention programmes offered by health services to people with diabetes in the non-disabled population (NICE, 2003; 2011). People with diabetes are encouraged to attend structured education programmes such as DAFNE, for adults with type 1 diabetes and receiving insulin therapy, or DESMOND, for adults with type 2, on addressing diet and exercise needs (Davies et al., 2008; Gillett et al., 2010). Neither are routinely offered to people with ID at a level that is appropriate to their needs, despite the need to make reasonable adjustments be made and person-centred care provided (Turner & Emerson 2013; Turner 2014). With appropriate education, people with ID can achieve a level of autonomy and improved quality of life (Taggart et al., 2015a; Rey-Conde & Lennox, 2007). Therefore, developing the ability of people with ID and diabetes to self-manage all or part of their condition is an area requiring attention and could make a contribution to improving overall diabetes management and control and the achievement of national diabetes standards (Shireman, 2010; Taggart et al., 2013). While there is an increasing interest in the development of self-management programmes for people with ID, there is wider evidence related to the benefits derived from self-management programmes, highlighting the need for further investigation (Wilson & Goodman 2011; Nolte et al., 2013; Forjuoh et al., 2014). In relation to diabetes self-management, a research focus on the modification and delivery of DESMOND to adults with intellectual disabilities is now being undertaken that may shed light on the usefulness of such approaches (Taggart et al., 2015a).

### **Strengths and shortcomings**

There are methodological strengths and limitations of the current study. A strength is the inclusion of a range of practitioners from across both services providing care and

support for people with ID and diabetes, not previously reported. Including additional social care provider organisations might have provided a wider perspective of issues. A further shortcoming is the absence of the views and experiences of more primary care physicians and primary care nurses who may be involved in the day-to-day management of diabetes in people with ID, such as administering insulin. Obtaining the views and experiences from people with ID and diabetes may have strengthened the findings by including their perspective, however this has been recently reported (see Cardol et al., 2012b; Whitehead et al., 2016).

## **Conclusion**

The current study highlights the experiences of practitioners involved in the care and support of this population, and sets out challenges and possible solutions where improvements can be made to service delivery and care. This study has identified where improvements can be made within diabetes and ID services to improve care and support, however further investigation is required to optimise care outcomes specific to this population. A recurring issue is related to the limited knowledge of people with ID about their diabetes and the availability of appropriate self-management education programmes to help educate people with ID and diabetes. In light of the apparent knowledge gap, variance in diabetes management and the opportunity to promote diabetes self-management, future research should examine the feasibility of adapting mainstream diabetes education and self-management programmes, such as DESMOND and DAFNE, to suit the needs of people with ID and diabetes and the impact on diabetes outcomes. Obtaining the views of people with ID in future diabetes research would provide evidence about their needs, ability to self-manage their diabetes and how education programmes and services made more accessible.

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**Table 1 – Participants by discipline**

ID service practitioners	Diabetes service practitioners	Primary care practitioner
<p><b>Specialist ID Health Services</b></p> <p>14 Specialist ID health practitioners from 3 teams:</p> <ul style="list-style-type: none"> <li>• 4 ID specialist clinical psychologists</li> <li>• 3 ID specialist nurses</li> <li>• 3 ID dieticians</li> <li>• 1 specialist ID physician</li> <li>• 1 community health service manager</li> <li>• 2 ID inpatient health service managers.</li> </ul> <p><b>Social Care Services</b></p> <p>5 support workers employed by a community residential service provider for people with ID.</p>	<p><b>Secondary Care</b></p> <p>9 Secondary care diabetes practitioners across 3 hospital out-patient clinic sites:</p> <ul style="list-style-type: none"> <li>• 3 Diabetes specialist physicians</li> <li>• 2 Diabetes specialist nurses</li> <li>• 2 Service managers</li> <li>• 1 dietician</li> <li>• 1 podiatrist</li> </ul>	<p><b>Primary Care</b></p> <p>1 primary care physician based within a community general practice.</p>

Table 2. Themes and sub-themes reported by participants according to discipline.

(Key: ID = Intellectual Disability services, D = Diabetes services, PCP = Primary Care Physician)

Themes & subthemes	Participant disciplines											
	Nurses		Physicians			Managers		Dieticians		Podiatrist	Psychologists	Support Workers
Theme 1: Enabling access to services to meet the diabetes care needs.	ID (N=3)	D (N=2)	ID (N=1)	D (N=3)	PCP (N=1)	ID (N=3)	D (N=2)	ID (N=3)	D (N=1)	D (N=1)	ID (N=4)	ID (N=5)
- The impact of cognitive limitations on diabetic service providers	✓	✓	✓	✓	✓	✓		✓			✓	✓
- Issues with care givers		✓		✓		✓		✓			✓	✓
- Time, accessible information & resources	✓	✓			✓	✓	✓	✓	✓	✓	✓	✓
Theme 2. Communication & Service Improvements												
- Supporting families & paid carers						✓	✓				✓	✓
- Effective multidisciplinary working	✓	✓				✓					✓	✓
- Education provision	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
- Service provision	✓	✓				✓	✓	✓			✓	✓
Theme 3. Person-Centred Care												
- Making adjustments to care and support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
- Accessible information & resources	✓	✓			✓			✓			✓	✓
- Managing care in mainstream services	✓		✓		✓	✓	✓	✓			✓	✓
Continuity of care	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓
- Diabetes management		✓		✓	✓		✓					✓
- Promoting self-care	✓				✓	✓					✓	✓